Final Report

October 2004

Select Special Health Information Act Review Committee

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Legislative
Assembly
of Alberta

EXECUTIVE SUMMARY OF COMMITTEE RECOMMENDATIONS

The Select Special Committee made the following recommendations for action, including amendments to the *Health Information Act* (HIA or the Act), where necessary to implement the recommendation.

1. A committee of the Legislature should be established early in 2005 to complete a focused review of several matters, including: *(see page 6)*

    - The scope of the *Health Information Act*, specifically related to the possible addition of privately funded health professionals, organizations with the primary purpose of providing health services that are not currently within scope, health clinics within post-secondary educational institutions and a new category of entity with a limited defined mandate to receive identifiable information for statistical analysis and research.
    - The purposes for which, and the rules governing what health information can be collected, used and disclosed in relation to any additional entities recommended for inclusion under the *Health Information Act*.
    - Continued inclusion of health service provider information within the scope of the *Health Information Act* and addition of provisions to allow access to identifiable health service provider information for research purposes.
    - Consideration of whether amendments to the *Health Information Act* are required to address the intent to harmonize rules in the pan-Canadian health information privacy and confidentiality framework.
    - Consideration of the need for more clear and transparent rules for the electronic health record.
    - The powers of the Information and Privacy Commissioner in overseeing the administration of the *Health Information Act*.

2. The seven key purposes in the Act should be retained in their current form. *(see page 8)*

3. The definition of "custodian" should be changed to reference s. 17(1)(a) of the *Regional Health Authorities Act*. *(see page 9)*

4. Alberta Health and Wellness should clarify terms and definitions in its guidelines for use by stakeholders. *(see page 9)*

5. Other government departments and local public bodies should not be brought within the scope of HIA, with the exception that health clinics whose primary purpose is health service provision within post-secondary educational institutions should be considered for inclusion by a committee of the Legislature established early in 2005. *(see page 11)*

6. Ambulance operators and ambulance services should be brought within the scope of HIA. *(see page 12)*

7. A committee of the Legislature should be established early in 2005 to consider the inclusion of some additional privately funded health professionals regulated by the *Health Professions Act*, and organizations with the primary purpose of providing health services. *(see page 12)*

8. The Workers' Compensation Board should not be included under HIA. *(see page 13)*

9. Alberta Blue Cross should not be brought within the scope of HIA. *(see page 13)*

10. Personal health information held by employers should not be brought within the scope of HIA. *(see page 14)*

11. A committee of the Legislature to be established in 2005 should consider the matter of continued inclusion of health service provider information within the scope of HIA. *(see page 18)*

12. A committee of the Legislature to be established in 2005 should consider the matter of access to identifiable health service provider information for research purposes on the same basis as access to identifiable health information about patients. *(see page 18)*

13. Business title and professional registration number should be included in the definition of health services provider information and disclosure should be authorized to any person for any purpose without consent, subject to existing exceptions in s. 37(2). *(see page 18)*

14. The definition of health information should not be changed to include non-recorded information. *(see page 19)*

15. The Act should be amended to "stop the clock" until the Information and Privacy Commissioner renders a decision on a custodian's request to disregard an access request under s. 87. *(see page 20)*

16. Exceptions to the individual's right to access the individual's own information be retained in their current form. *(see page 20)*

17. A review of the fees for access to health information records should be deferred to the Regulation Review in 2005. *(see page 21)*

18. A committee of the Legislature established early in 2005 should consider the need for more clear and transparent rules for the electronic health record. *(see page 21)*

19. A provision should be added to HIA to allow for the collection, use and disclosure of a unique identifier for health service providers for authorization and authentication purposes in the electronic health record. *(see page 22)*

20. No changes are required to the duty to collect health information directly from the individual except as authorized. *(see page 22)*

21. Provisions respecting collection of health information for public health purposes should be considered by a committee of the Legislature early in 2005 when additional health service providers are considered for inclusion with the scope of the *Health Information Act*. *(see page 22)*

22. Provisions respecting the collection of information about the individual's family health history without the consent of family members should not be amended. *(see page 23)*

23. The duty to inform individuals about information collection practices should be reviewed by a committee of the Legislature early in 2005 when the pan-Canadian health information privacy and confidentiality framework is finalized. *(see page 23)*

24. No changes are required to the current list of purposes for the use of individually identifying health information without consent. *(see page 25)*

25. The new committee of the Legislature should consider the list of authorized purposes for the use of identifying health information when it reviews the addition of health service providers and health service organizations early in 2005. *(see page 25)*

26. A committee of the Legislature should consider the matter of consent in early 2005 when the pan-Canadian health information privacy and confidentiality framework is finalized. *(see page 26)*

27. The Act should be amended to allow for disclosure of individually identifiable diagnostic, treatment and care information without consent to: *(see page 27)*

    - Health departments of provincial, territorial and federal governments for health services provided to persons under their jurisdiction
    - Alberta government departments or federal government departments for determining eligibility to receive a health service or a health-related service or benefit, or for payment purposes
    - Third parties for payment purposes
    - A successor where the custodian remains a custodian but transfers records
    - First Nations police services on the same basis as permitted to other police services

28. The Act should be amended for consistency with the *Health Professions Act* to authorize professional bodies to retain health information used in an investigation or a hearing for 10 years instead of destroying the information at the earliest opportunity. *(see page 27)*

29. The Act should not be amended to authorize disclosure of individually identifiable diagnostic, treatment and care information without consent to: *(see page 27)*

    - Collaborative or integrated programs
    - The Canadian Medical Protective Association for medical-legal purposes
    - The clergy or to "any person", the presence and location of an individual in a health facility
    - Any person to address a complaint or allegation made in a public forum

30. The Act should not be amended to: *(see page 28)*

    - Remove ability to disclose to the Chief Electoral Officer
    - Restrict disclosure without consent to purposes related to direct care and treatment
    - Require the individual to be notified before disclosure without consent
    - Allow disclosure of psychological raw test and data scores only to those qualified to interpret them

31. The Act should be amended to mandate disclosure, without consent, to police services of: *(see page 30)*

    - Patient name
    - Address/location in facility
    - Date of admission
    - Name of physician
    - Nature of injury

    When:

    - For purposes of obtaining a warrant or subpoena, and when the police have reasonable grounds to suspect that the person seeking health services has been involved in some form of criminal activity; and make a request for that information, or
    - A custodian has reasonable grounds to suspect that the person seeking health services has been involved in some form of criminal activity

32. The Act should be amended to mandate disclosure of limited health information without consent to police services where a custodian has reasonable grounds to suspect a prescription reveals or tends to reveal that an offence has been committed or is being attempted, including the individual's name, address, date of birth, personal health number, the drug, dosage, prescriber's name and address, a copy of the prescription, and any other health information contained on the prescription. *(see page 30)*

33. The Government of Alberta should consider introducing separate stand-alone legislation requiring mandatory reporting by custodians to police services of gunshot wounds, stabbings and severe beatings. *(see page 31)*

34. The Act should be amended to allow the disclosure of health information, without consent, by Alberta Health and Wellness or other custodians to police services where there is reason to believe that an individual has committed fraud in obtaining Alberta health care insurance coverage, health services or health benefits from the publicly funded health system. *(see page 31)*

35. The Act should be amended to provide explicit authority for the Triplicate Prescription Program. *(see page 31)*

36. Provisions respecting genetic information should be considered by a committee of the Legislature in early 2005 when the pan-Canadian health information privacy and confidentiality framework is finalized. *(see page 32)*

37. A committee of the Legislature should review consent requirements under the *Health Information Act* in early 2005 when the pan-Canadian health information privacy and confidentiality framework is finalized. *(see page 33)*

38. A committee of the Legislature established early in 2005 should consider a new category of entity under the Act with a limited defined mandate to receive identifiable information for statistical analysis and research. *(see page 34)*

39. The term "ethics committee" should be changed to "research ethics board". *(see page 34)*

40. The Information and Privacy Commissioner should be authorized to publish ethics committee research approvals on a website with an explanatory note that the research has not necessarily been conducted and that health information has not necessarily been disclosed. *(see page 34)*

41. No changes should be made to ethics committee duties, composition or number; consent requirements and surrogates; requests for clarification or the requirement to consider the least amount of information and highest level of anonymity for the research purpose. *(see page 34)*

42. Alberta Health and Wellness should consider the need for information manager provisions, information manager agreements, application of these provisions to custodians who are also information managers and the relationship between information manager provisions and affiliate provisions prior to the next full review of the Act by a committee of the Legislature. *(see page 35)*

43. The requirement to note every disclosure of individually identifiable health information without consent should be retained and amended to not require notation of the purpose of the disclosure when the disclosure is made electronically through a system with automated audit capability. *(see page 36)*

44. Alberta Health and Wellness should consult with stakeholders about the required period of retention for disclosure notations prior to the next full review of the Act by a committee of the Legislature. *(see page 36)*

45. The requirement for written notification to the recipient of the purpose and authority for disclosure of diagnostic, treatment and care records should be retained, but amended to make explicit that the requirement does not apply where the disclosure is to the individual the information is about, and the disclosure is not in response to a formal application for access by the individual. *(see page 36)*

46. No changes should be made to provisions respecting custodian duties in relation to affiliates, duties to protect health information outside Alberta, data matching, collection of the least amount of information necessary for the purpose, and privacy impact assessments. *(see page 37)*

47. A committee of the Legislature established early in 2005 should consider the Information and Privacy Commissioner's request for explicit powers to audit and compel information for an audit. *(see page 37)*

48. A committee of the Legislature should consider the Information and Privacy Commissioner's request for explicit powers to enter into extra-provincial agreements and to consult and delegate extra-provincially, in 2005. *(see page 38)*

49. A committee of the Legislature should consider the matter of "orphan records" in 2005. *(see page 38)*

50. The Act should not be amended to include a penalty for making repeated requests judged by the Commissioner to be vexatious, to extend the Commissioner's powers to include all entities with health information, to add a power to rule on miscarriage of justice, to deal with the process for privacy impact assessments, or to allow for release of the name of an affiliate who discloses a breach by a custodian to the Commissioner. *(see page 39)*

51. The Duty to Comply with Order provisions of the Act should not be amended. *(see page 39)*

52. The Act should be amended to provide a limited authority for a "next friend" or guardian ad litem to exercise the rights or powers of the individual where the exercise relates to the powers and duties of the next friend or guardian ad litem. *(see page 40)*

53. Alberta Health and Wellness should review the matter of substitute decision-makers for consideration by a committee of the Legislature during the next full review of the Act. *(see page 40)*

54. The offences and penalties under the Act should not be amended. *(see page 41)*

55. The Health Information Regulation should be updated to: *(see page 41)*

    - Delete s. 1(2), and the reference in s. 6(2) to the repealed HIA s. 59
    - Replace in s. 2(b) the "Billing Practice Advisory Committee" with "a committee of an organization referred to in s. 18(4) of the *Alberta Health Care Insurance Act*"
    - Replace the reference to the *Child Welfare Act* in s. 4 to the *Child, Youth and Family Enhancement Act* when it comes into force

56. The requirements in the Regulation specifying matters to be addressed in a written agreement respecting information to be stored, used or disclosed outside Alberta should be retained. *(see page 42)*

57. Alberta Health and Wellness should consult with stakeholders and develop a regulation respecting retention, disposal and archival storage of records as part of the review of the Regulation in 2005. *(see page 42)*

58. Alberta Health and Wellness should consult with stakeholders to determine whether principles for technical, physical or administrative security should be added to the Regulation in 2005. *(see page 42)*

59. The Health Information Regulation should not be amended to include reference to the *Electronic Transactions Act* or to include the scope and content of information manager agreements. *(see page 43)*

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MANDATE

On April 2, 2004, the Legislative Assembly of Alberta passed a motion appointing an all-party Committee to review the *Health Information Act*, as set out in section 109(1) of the Act. The review included a review of the application of the Act to departments of the Government of Alberta and to local public bodies, as defined in the *Freedom of Information and Protection of Privacy Act*, as well as other entities that are not custodians and have personal health information of individuals in their custody or control.

The Committee membership is:

Mr. Broyce Jacobs, MLA, Chair
Cardston-Taber-Warner (PC)

Ms Karen Kryczka, MLA, Deputy Chair
Calgary-West (PC)

Ms Laurie Blakeman, MLA
Edmonton-Centre (LIB)

Mr. Dave Broda, MLA
Redwater (PC)

Mr. Hector Goudreau, MLA
Dunvegan (PC)

Mr. Rob Lougheed, MLA
Clover Bar-Fort Saskatchewan (PC)

Mr. Thomas Lukaszuk, MLA
Edmonton-Castle Downs (PC)

Mr. Hugh MacDonald, MLA
Edmonton-Gold Bar (LIB)

Dr. Raj Pannu, MLA
Edmonton-Strathcona (ND)

Mr. Lloyd Snelgrove, MLA
Vermilion-Lloydminster (PC)

INTRODUCTION

Alberta's *Health Information Act* (HIA or the Act) became law on April 25, 2001. This legislation protects the privacy of Albertans and the confidentiality of their health information. It balances the protection of privacy and confidentiality with the need to enable health information to be shared and accessed where appropriate, to provide health services and to manage the health system.

This legislation provides individuals with the right to access their own information and to have that information protected from inappropriate collection, use and disclosure.

The legislation requires that a Special Committee of the Legislative Assembly begin a comprehensive review of this Act within three years after coming into force.

Alberta is one of three provinces that have enacted sector specific health information legislation recognizing the unique characteristics of personal health information. The rules in the HIA are based on a set of internationally accepted fair information principles. In general terms, the Act extends to Albertans two basic rights. The first is the right to privacy and confidentiality of the individual's health information. The second is the right to access their own information in the custody or under the control of custodians including the right to examine, obtain a copy of, or request a correction or amendment to recorded personal health information.

The rights of Albertans are reflected in the provisions of the HIA and the duties and obligations placed on custodians to protect information from unauthorized collection, use and disclosure. The Act provides for independent reviews of decisions made by custodians under the Act by Alberta's Office of the Information and Privacy Commissioner.

During the three years that the Act has been in force, there have been significant developments which have influenced the review of the collection, use, disclosure and protection rules detailed in the HIA, including:

- Canada's *Personal Information Protection and Electronic Documents Act* (PIPEDA) came into force on January 1, 2004 for health entities in Alberta such as private pharmacies, laboratories and health care providers in private practice
- The *Personal Information Protection Act* (PIPA) came into effect on January 1, 2004
- The implementation of Alberta's province-wide Electronic Health Record; and
- The development of the pan-Canadian health information privacy and confidentiality framework

The Committee's review focused upon:

- The Act and its supporting policies and administration to determine whether an appropriate balance has been achieved between protection of the individual's privacy and access to health information where appropriate to provide health services and to manage the health system

- The application of this Act
    a. *to departments of the Government* of Alberta
    b. to local public bodies as defined in the *Freedom of Information and Protection of Privacy Act*, and
    c. to any other entity that is not a custodian and has information about the health of an individual in its custody and under its control
- The impact of electronic health records on the HIA rules
- Whether the recommended amendments to the HIA address the intent to harmonize rules in the pan-Canadian health information privacy and confidentiality framework

This review did not include:

- Protection of personal information and privacy under the purview of the *Protection of Personal Information Act* (PIPA) except for health information contained in employee health records
- Access/privacy and confidentiality protection of personal information in the *Freedom of Information and Protection of Privacy Act* (FOIP)

ACKNOWLEDGEMENTS

The Committee wishes to acknowledge the many individuals, organizations and stakeholders who submitted written briefs and letters, and those who appeared before the Committee. These submissions provided information and insight into the workings of the *Health Information Act* as it applies to the various government departments, public entities and others charged with the custody of personal health information.

The Committee also wishes to acknowledge the invaluable assistance of the technical and administrative support staff assigned to the Committee:

TECHNICAL SUPPORT TEAM

Alberta Health and Wellness
Ms Linda Miller - Director, Information Management, Health Accountability
Ms Wendy Robillard - Team Leader, Research Access and Policy Support Team
Ms Evelyn Swanson - Policy Lead, Health Information Act Review
Ms Catarina Versaevel - Project Director, Health Information Act

Alberta Justice
Ms Holly Gray - Solicitor, Health and Wellness
Ms Heather Veale - Solicitor, Health and Wellness

Office of the Information and Privacy Commissioner
Ms Roseanne Gallant - Compliance Officer
Ms Noela Inions - Legal Counsel

ADMINISTRATIVE SUPPORT TEAM

Legislative Assembly Office
Mrs. Corinne Dacyshyn - Committee Clerk
Mrs. Karen Sawchuk - Committee Clerk
Ms Rhonda Sorensen - Communications Coordinator, Office of the Clerk

Alberta Health and Wellness
Ms Stacy Groenewegen - Administrative Support

THE CONSULTATION PROCESS

In June 2004, the "Select Special Health Information Act Review Committee Consultation Guide" was distributed to stakeholders and made available on the Committee's website. Written responses were received from 72 stakeholders. The number of stakeholders who responded in each category appears in the table below.

Stakeholder Category	Number
Municipal Government Sector	16
Health Authorities	7
Professional Colleges/Associations	7
Health Service Provider Organizations	8
Insurance Sector	5
Other Private Sector	10
Police Services	3
Universities	2
Health Information and Research	4
Advocacy and Faith-Based Organizations	3
Individuals	3
Information and Privacy Commissioner	1
Workers' Compensation Board	1
Government Sector	2
Total Stakeholders	**72**

A list of individuals and organizations that provided written submissions to the Committee is presented in Appendix A. Although a total of 72 organizations and individuals provided written input, many commented on only one or two questions that were of the most relevance to them. For example, most of the 16 responses from the municipal government sector dealt only with matters related to inclusion of ambulance services under the Act.

In addition to receiving written submissions, the Committee heard oral presentations from 15 organizations, including the Office of the Information and Privacy Commissioner, Alberta Medical Association, Health Boards of Alberta, Workers' Compensation Board, Pharmacists' Association of Alberta, Alberta College of Pharmacists, Canadian Mental Health Association, Consumers' Association of Canada (Alberta) and the Edmonton and Calgary Police Services. A complete list of those providing oral presentations appears in Appendix B.

THE REVIEW PROCESS

The Committee reviewed the issues identified through the consultation process and, in light of the impending election call, prioritized the matters that could be considered in the time available to complete its work. The Committee completed its analysis of these issues and developed recommendations that are listed in the next section of the report along with a summary of stakeholder input and the Committee's deliberations.

Some important issues could not be fully addressed due to the need for additional research and further consultations with stakeholders. In addition, the pan-Canadian health information privacy and confidentiality framework had not been finalized by the time of the Committee's report, and the matter of harmonization with the framework could therefore not be addressed. As a result, the Committee concluded some matters should be deferred to a future committee of the Legislature.

The Committee recommended that:

1. **A committee of the Legislature should be established early in 2005 to complete a focused review of several matters including:**
   - **The scope of the *Health Information Act*, specifically related to the possible addition of privately funded health professionals, organizations with the primary purpose of providing health services that are not currently within scope, health clinics within post-secondary educational institutions and a new category of entity with a limited defined mandate to receive identifiable information for statistical analysis and research.**
   - **The purposes for which, and the rules governing what health information can be collected, used and disclosed in relation to any additional entities recommended for inclusion under the *Health Information Act*.**
   - **Continued inclusion of health service provider information within the scope of the *Health Information Act* and addition of provisions to allow access to identifiable health service information for research purposes.**
   - **Consideration of whether amendments to the *Health Information Act* are required to address the intent to harmonize rules in the pan-Canadian health information privacy and confidentiality framework.**

- Consideration of the need for more clear and transparent rules for the electronic health record.
- The powers of the Information and Privacy Commissioner in overseeing the administration of the *Health Information Act*.

COMMITTEE RECOMMENDATIONS

PURPOSES OF THE ACT

The Committee reviewed the seven key purposes of the *Health Information Act* (HIA or the Act) and considered stakeholder input about the purposes. The Committee also considered input in response to the suggestion of an additional purpose "to establish mechanisms to ensure transparency and accountability for the collection, use and disclosure of personal health information."

The general consensus of stakeholders who responded to this question was that the purposes are appropriate as written, and the addition of a purpose related to transparency and accountability was unnecessary and could be confusing. The Committee considered suggestions to add a preamble to the Act giving primacy to the principle of least amount of information and the highest degree of anonymity, to remove the first purpose regarding establishment of mechanisms to protect the privacy of individuals and the confidentiality of their health information and to add public health as a key purpose of the Act. The Committee decided that no changes were required.

(Reference consultation question 1 in Appendix C)

The Committee recommended that:

2. The seven key purposes in the Act should be retained in their current form

DEFINITIONS

The Committee asked stakeholders whether any definitions in the Act should be modified. Many stakeholders who commented on definitions focused on the definitions of custodian, affiliate and health services as they relate to questions of scope of the Act. These were considered in the context of discussions about scope.

Several stakeholders commented about the need for clarity in the definition of affiliate and the information manager. These are considered in the context of discussions about the duties and obligations of custodians.

Other suggestions including those related to genetics, research and health services provider information are dealt with in the relevant sections of this report.

Most other suggestions were unique to a particular stakeholder, and many were for clarification of existing definitions or other terms used in the Act. The Committee concluded that Alberta Health and Wellness could address these requests through its guidelines as necessary. One update was suggested in the definition of custodian to reference the correct section of the *Regional Health Authorities Act*, s. 17 (1)(a).

(Reference consultation question 2 in Appendix C)

The Committee recommended that:

3. **The definition of "custodian" should be changed to reference s. 17 (1)(a) of the *Regional Health Authorities Act*.**

4. **Alberta Health and Wellness should clarify terms and definitions in its guidelines for use by stakeholders.**

SCOPE OF THE ACT

The Committee was asked to provide advice on whether the scope of the Act should be expanded to include other departments of the Government of Alberta, local public bodies as defined in the *Freedom of Information and Protection of Privacy Act*, and any other entity that is not a custodian and that has health information about the health of an individual in its custody or under its control.

The HIA applies to "custodians" of health information primarily in the publicly funded health sector. Current custodians include:

- The Minister and Alberta Health and Wellness
- Regional Health Authorities (RHAs)
- Alberta Cancer Board
- Alberta Mental Health Board
- Hospitals and nursing homes not directly operated by the RHAs or boards
- Health service providers paid under the Alberta Health Care Insurance Plan (i.e. physicians, chiropractors, dental surgeons, dental mechanics, opticians, optometrists, podiatrists and osteopaths)
- Pharmacists and pharmacies regardless of how they are paid
- Boards, agencies, committees and other organizations designated in the regulations

The Act also applies to "affiliates" of custodians. These include employees, agents, contractors, volunteers and

physicians paid by a custodian or having privileges with a custodian. The Alberta Alcohol and Drug Abuse Commission and Persons with Developmental Disabilities Boards are excluded. Ambulance operators are also excluded.

The Provincial Steering Committee on the *Health Information Act* recommended in 1998 that health information rules should apply to both public and private sectors in order to create a level playing field and ensure privacy is protected regardless of whether the custodian is a public or private sector entity. The government did not accept the recommendation but determined a committee of the Legislative Assembly should review the matter after three years of experience with the Act.

HIA creates a "controlled arena" within which custodians can collect, use and disclose health information without consent for the purposes listed in the Act. It also includes privacy protections for individuals and health service providers respecting disclosure outside the controlled arena, and creates rights of access for the individual to the individual's own information.

The government departments and local public bodies that are currently outside the scope of HIA are covered by the *Freedom of Information and Protection of Privacy Act* (FOIP). FOIP protects the privacy of personal information held by public bodies and creates rights of access by the individual to general and personal information. This includes information about the individual's health and health care when the information is not held by a custodian under HIA. This means that health information held by public bodies is subject to privacy protections and individual access rights under either HIA or FOIP.

Since HIA was introduced, additional privacy legislation has been proclaimed for the private sector. The *Personal Information Protection Act* (PIPA) is provincial legislation that provides privacy protections for the individual's personal information, including protection for employees of private sector organizations.

The *Personal Information Protection and Electronic Documents Act* (PIPEDA), the federal legislation for the private sector, provides privacy protection for the individual's personal information, including information about health and health care, and creates rights of access to one's own personal information. This includes protection for employees of federally regulated organizations.

All entities that provide health services in Alberta, or that hold health information about individuals are covered by one or more privacy acts. It was noted that the privacy protections and rights of individual access provided in these other statutes vary. However, the protections appear to be adequate for health information currently outside the scope of HIA, particularly where the health information is not collected for purposes of health service delivery. The Committee concluded the primary question for inclusion under HIA at this time is whether any additional health professionals or health service organizations should be brought into the "controlled arena", and the rules that should apply to their collection, use and disclosure of health information within the arena.

There was very little support for inclusion of Alberta Government departments and local public bodies because they are adequately covered by FOIP, and have worked to refine their protections and access procedures over the last ten years. The Committee agreed with stakeholders that there was not sufficient benefit to the public to warrant the additional burden of administering health information under HIA.

However, the University of Alberta and University of Calgary suggested including universities as custodians with respect to a health clinic owned or operated by a university, whose primary purpose is health service provision. They argued that physicians who work in university clinics are custodians and rely on university infrastructure for service delivery, including introduction of the electronic health record. The university has no real authority or responsibility to ensure a consistent response to compliance with HIA, but it owns and operates the electronic networks, provides billing and transcription services to physicians, staffs and supervises administrative positions, is responsible for storage and retrieval of health information and sets policy for the clinics. The Universities of Alberta and Calgary believe they should be custodians and should have operational authority for managing compliance with HIA.

(Reference consultation question 3 in Appendix C)

The Committee recommended that:

5. **Other government departments and local public bodies should not be brought within the scope of HIA, with the exception that health clinics whose primary purpose is health service provision within post-secondary educational institutions should be considered for inclusion by a committee of the Legislature established early in 2005.**

The Committee's consultation revealed consensus that ambulance operators and ambulance services should be brought within the scope of HIA. Ambulance services are an integral part of the health system and will soon be governed and funded by Regional Health Authorities. Inclusion within HIA will bring benefits for patients through better information sharing between ambulance attendants and other custodians.

(Reference consultation question 4 in Appendix C)

The Committee recommended that:

6. **Ambulance operators and ambulance services should be brought within the scope of HIA.**

There was also considerable support for bringing the other health professions regulated under the *Health Professions Act* and health service organizations within the scope of HIA. Stakeholders suggested that any entity that may contribute to and have access to the provincial electronic health record in the future should fall within the scope of the Act. Both publicly funded and privately funded health services delivered by health professionals and organizations with health service delivery as their primary purpose were suggested for inclusion.

However, the Committee noted that few health service organizations currently outside the scope of HIA, and no health professions currently outside the scope of HIA participated in the consultation. Their views about inclusion are not known and their needs for health information from other custodians are not clear. The Committee concluded that deferral of a decision about their inclusion would be appropriate until these entities have an opportunity to participate in consultation. The Committee also noted that in the meantime, adequate privacy protections and access rules apply to these bodies through other legislation. In addition, time is required to complete implementation of the electronic health record across the province with existing custodians, before new custodians can be included.

(Reference consultation questions 3 and 5 in Appendix C)

The Committee recommended that:

7. **A committee of the Legislature should be established early in 2005 to consider the inclusion of some additional privately funded health professionals regulated by the *Health Professions Act*, and organizations with the primary purpose of providing health services.**

Stakeholders who commented were generally in agreement that the Workers' Compensation Board (WCB) should not fall within the scope of the Act. The individual health information held by the WCB is seen to be adequately protected and individuals have access rights to information about their health and health care through FOIP and the *Workers' Compensation Act*. In addition, there were concerns about potential loss of privacy for workers if WCB is included as a custodian and gains access to health records that are not related to their work injuries.

(Reference consultation question 8 in Appendix C)

The Committee recommended that:

8. **The Workers' Compensation Board should not be included under HIA.**

Stakeholders who commented on the matter generally did not support inclusion of Alberta Blue Cross (ABC). Government-subsidized plans for seniors and individuals administered by ABC on behalf of Alberta Health and Wellness are already under HIA. For these plans, ABC is an affiliate to Alberta Health and Wellness. Other government-funded benefit plans administered by ABC for other departments fall under FOIP. ABC's employer group plans and individual plans fall under PIPA and/or PIPEDA.

Some stakeholders suggested that ABC should be treated in the same way as other insurers to avoid an unfair advantage or to ensure a level playing field for insurers. Insurers should not be custodians because (1) allowing insurers' access to information in the "controlled arena" would reduce individual privacy and confidentiality, and (2) insurers are not health service providers. Information held by insurance companies falls under PIPA or PIPEDA.

(Reference consultation question 9 in Appendix C)

The Committee recommended that:

9. **Alberta Blue Cross should not be brought within the scope of HIA.**

There was also considerable consensus that adequate privacy and access protections are in place through FOIP, PIPA or PIPEDA for health information held by employers in employee records. Employers expressed concerns about the potential costs and administrative burden involved in administering their employee files under two different pieces of legislation if personal health information is to be treated differently than other personal information.

(Reference consultation question 7 in Appendix C)

The Committee recommended that:

10. Personal health information held by employers should not be brought within the scope of HIA.

HEALTH SERVICE PROVIDER INFORMATION

Health service provider information was included under HIA to ensure transparency to health service providers about the ways information about them could be used and when it could be disclosed.

Alberta Health and Wellness and other custodians (e.g. pharmacies) hold electronic data about the practice of physicians. In the case of Alberta Health and Wellness, this is a by-product of billing information for physician services. In the case of pharmacies, this is a by-product of filling prescriptions. Physicians maintain that their identifiable information should be used appropriately by custodians and protected from unauthorized use and disclosure without consent.

Other than disclosure to professional bodies and disclosure of basic "business card" information, the Act permits disclosure to non-custodians only if it is authorized or required by an enactment of Alberta or Canada, or if the provider consents to its disclosure.

The policy intent was to require that custodians obtain the provider's consent for disclosing identifiable health service provider information to non-custodians for use by non-custodians for a commercial purpose.

Stakeholders were asked to comment on whether health service provider information should be included within the scope of the Act. Apart from the pharmacy-related stakeholders and the Consumers' Association of Canada (Alberta), others who commented were more likely to support the current provisions as appropriate, or support the approach but suggest protections might be better placed in other legislation such as professional legislation (Aspen RHA) or FOIP (Universities).

Physicians, represented by the Alberta Medical Association (AMA) and the College of Physicians and Surgeons of Alberta expressed strong support for continued inclusion and protection of health service provider information, including professional practice information. The AMA registered strong objections to the current practice of selling prescribing information about identifiable physicians for commercial purposes without express consent, and against the express wishes of many physicians.

The Alberta Pharmacists' Association does not support inclusion of health service provider information in HIA, and commented that requiring consent for disclosure of health service-provider information will compromise current and future programs for quality improvement, program review, health system management and research.

Pharmacy-related stakeholders view the current protections for health service provider information as too broad or inappropriate under HIA. Some suggested multiple alternatives that they believe would be appropriate. Their suggestions include:

- Remove health service provider information from the Act, or
- Change or add definitions (i.e. "other information") so only limited, specified information would be protected and practice information would not be protected, or
- Change the conditions for protection in 37(2)(a) and (b) so practice information would be protected only where it would reveal "other information" about the provider and there is reason to believe the disclosure could result in physical, mental or financial harm to the health service provider, or
- Remove the protections in 37(2)(a) and (b) that allow disclosure only if "other information" is not revealed or there is reason to believe the disclosure could result in physical, mental or financial harm, thus allowing disclosure to any person for any purpose without consent, or
- Remove the prohibition on commercial use of the information and allow commercial use unless the commercial use could be expected to cause undue financial harm to the health service provider

All of these suggestions would likely have the effect of allowing the continued disclosure/sale of identifiable physician prescribing information.

In addition, a suggestion was made to allow the disclosure of health service provider information for research purposes on the same basis as patient information, including ethics review and custodian consideration of the least amount of information and highest level of anonymity necessary for the research purpose.

The central issue identified through the consultation is disclosure of identifiable information without consent about the professional practice of one health professional by another health professional to a non-custodian for analysis and subsequent disclosure in identifiable form.

Submissions included reference to the situation in other jurisdictions, and the Committee requested clarification and additional background. In British Columbia, the Bylaws of the College of Pharmacists (Bylaws) specifically prohibit the release of information for commercial purposes if it would permit the identity of the practitioner or the patient to be determined. Information may be released for non-commercial purposes in accordance with the *Pharmacists, Pharmacy Operations and Drug Scheduling Act*, the Bylaws, or with the express consent of the practitioner, patient and pharmacy manager. Pharmacists and the PharmaNet Committee (the Committee that administers the provincial drug data-base called PharmaNet) are not allowed to disclose patient records, including the physician's name, for purposes of market research. Provider-identifying PharmaNet information cannot be disclosed for research purposes in general under B.C.'s current pharmacy legislation. B.C.'s FOIP Act indicates information cannot be disclosed if it is an unreasonable invasion of a third person's personal privacy. Disclosure of a name to be used for solicitations is presumed to be an unreasonable invasion.

In Saskatchewan, a regulation is being proposed under the *Health Information Protection Act*. According to the consultation paper, "The *Health Information Protection Act* Regulations DRAFT for Consultation" the proposed regulation "will protect the privacy of prescribing information by preventing Saskatchewan pharmacies from disclosing information about another trustee (e.g. physician) that is collected by pharmacies along with personal health information about an individual." If the regulation is passed, "pharmacies will only be able to disclose information about another trustee (e.g. physician) for a purpose that is consistent with the reason the information was initially collected." These regulations will not apply to statistical or de-identified information where the provider cannot be reasonably identified.

Manitoba's *Personal Health Information Act* does not apply to health service provider information and the *Pharmaceutical Act* does not address the matter. The Manitoba Ministry of Health is subject to the Manitoba FOIP Act. The Ministry holds drug-prescribing information

in its databases, and does not disclose the physician's name without consent. The Manitoba Pharmaceutical Association (MPA) is the regulatory body for pharmacists in Manitoba. The Council of the MPA passed a motion February 18, 2002, which proposes that the "Council remain with the status quo and pharmacies are instructed not to release prescriber information to prescription data collectors which is consistent with the wishes of the College of Physicians and Surgeons".

Ontario will implement its new health information privacy legislation this fall. It did not include protections for health service provider information in the legislation.

Quebec's *An Act Respecting the Protection of Personal Information in the Private Sector* applies to personal information, which is defined as any information that relates to a natural person and allows that person to be identified. The Act was amended in 2001 to add section 21.1 dealing with "Information on Professionals". Under this section, the Commission d'accès à l'information (Commission) may, on written request and after consulting the profession concerned, grant a person authorization to receive personal information on professionals regarding their professional activities, without consent, if:

- The Commission has reasonable cause to believe the communication protects professional secrecy
- It does not allow identification of the person to whom the professional service is rendered, and
- It does not otherwise invade the privacy of the professionals concerned
- The professionals concerned will be notified periodically of the intended uses and given opportunity to refuse the use or preservation of the information, and
- Security measures are in place to ensure confidentiality of personal information

The Quebec legislation also allows the Commission to grant authorization for a person to receive personal information for study, research or statistical purposes without consent, if it is of the opinion that the intended use is not frivolous, and the ends cannot be achieved without identifiable information, and the information will be used in a manner that will ensure its confidentiality. Any authorization is granted for a set period and on any

conditions imposed by the Commission.

The Commission has power to revoke the authorization if it believes the person authorized does not respect confidentiality or other conditions imposed.

The former Federal Privacy Commissioner issued a decision under PIPEDA after complaints were filed, that physician prescribing information is work product and not personal information. As a result, the information is not protected under PIPEDA.

The Committee discussed the potential benefits to the public, patients, researchers, pharmaceutical manufacturers, the health system and physicians themselves of identifiable health service provider information being widely available. The Committee also considered the potential implications of changing the current protections for health service provider information, the implications of allowing identifiable health service provider information to be disclosed for research purposes, and the possibility of an explicit prohibition on the collection, use and disclosure of identifiable health information for research and marketing purposes.

The Committee considered a 'housekeeping' request from the Government of Alberta, to include business title and professional registration number in the definition of health services provider information and to authorize disclosure to any person for any purpose without consent, subject to existing exceptions in s. 37(2).

(Reference consultation question 6 in Appendix C)

The Committee recommended that:

11. A committee of the Legislature to be established in 2005 should consider the matter of continued inclusion of health service provider information within the scope of HIA.

(Reference consultation questions 6 and 28 in Appendix C)

12. A committee of the Legislature to be established in 2005 should consider the matter of access to identifiable health service provider information for research purposes on the same basis as access to identifiable health information about patients.

(Reference consultation question 6 in Appendix C)

13. Business title and professional registration number should be included in the definition of health services provider information and disclosure should be authorized to any person for any purpose without consent, subject to existing exceptions in s. 37(2).

NON-RECORDED HEALTH INFORMATION

The current scope of the Act includes recorded health information that is documented, recorded or stored in any form, on any storage medium and by any means. Non-recorded information is included to the extent that a custodian may collect, use or disclose non-recorded information only for the purpose for which the information was provided to the custodian. Failure to comply with the Act, including this provision, is an offence subject to fines. HIA is consistent with FOIP, PIPA and PIPEDA, which only provide access to recorded information Stakeholders were asked whether non-recorded information should be included more fully under the HIA, including extension of a right of access to the individual's non-recorded information. The stakeholder organizations that commented were in agreement that the definition of health information should not include non-recorded information. Many cited practical problems granting access to information that is not recorded, and to determining how it was used or disclosed. It would be difficult to prove or disprove the existence of such information if an applicant complains. Many stakeholders also noted that non-recorded information was sufficiently protected through professional practice guidelines and existing provisions of the Act. The Committee agreed with this perspective.

(Reference consultation question 10 in Appendix C)

The Committee recommended that:

14. The definition of health information should not be changed to include non-recorded information.

INDIVIDUAL RIGHT TO ACCESS HEALTH RECORDS

The Act sets out the individual's right to access any record containing health information about the individual that is in the custody or under the control of a custodian. The right to access health information is subject to limited and specific exceptions set out in the Act.

An individual also has a right to request correction or amendment of health information about him or herself and the Act specifies the timelines for a response from the custodian. The Regulations under the Act set out the maximum amount of fees that can be charged.

The majority of organizations commenting view the process for obtaining access as appropriate, and support the 30-day timeline, providing the initial request is clear from the start time.

Clarification was requested on who can serve as an authorized representative and a specific suggestion was made for substitute decision-makers. These matters are addressed in the section of the report dealing with substitute decision-makers.

Two stakeholder groups expressed concerns about access requests that are viewed as vexatious. Section 87 of HIA enables custodians to seek approval of the Information and Privacy Commissioner (Commissioner) to disregard an access request if, because of its repetitious or systematic nature, the request would unreasonably interfere with the operations of the custodian or amount to an abuse of the right to make those requests, or one or more of the requests are frivolous or vexatious. However, current provisions do not "stop the clock" when an application is made to disregard a request. HIA requires a response within 30 days, but the Commissioner's review can take longer than the 30 days.

The Committee considered the amount of time required by the Commissioner for due process in reviewing a request to disregard and the possibility of setting a time limit on the Commissioner's response. The Committee also considered the implications of requiring or not requiring a custodian to continue processing an access request during this time. The Committee concluded that the custodian should be allowed to discontinue processing a request while it is under the Commissioner's review.

(Reference consultation questions 11. and 12. in Appendix C)

The Committee recommended that:

15. The Act should be amended to "stop the clock" until the Information and Privacy Commissioner renders a decision on a custodian's request to disregard an access request under s. 87.

Stakeholders who commented were generally in agreement that the exceptions to the individual's right to access the individual's own information were appropriate. It was suggested that health information a researcher uses solely for research be exempt from access provisions. Upon review, it was determined that this is already the case under HIA for non-custodian researchers. Access provisions apply only to health information gathered by custodians and affiliates for research purposes.

(Reference consultation question 12. in Appendix C)

The Committee recommended that:

16. Exceptions to the individual's right to access the individual's own information be retained in their current form.

Opinion was divided on the question of whether fees that can be charged by a custodian for processing an access request are appropriate. The majority of health authorities and others representing custodians indicated the fees do not cover the costs involved. One suggested a need to determine processing costs for electronic records.

An advocacy group, insurance organization and an individual see the fees as too high, and a potential limit on the individual's rights based on ability to pay. A few stakeholders suggested the current fees are appropriate.

The Committee considered both the need to ensure that custodians are adequately compensated for the work of processing a request and the costs of the media involved (e.g. radiology film, paper, etc.), and the need to ensure that fees are reasonable and not prohibitive for individuals. It noted that the fee schedule is contained in the Health Information Regulation that is to be reviewed by November 2005.

(Reference consultation question 13 in Appendix C)

The Committee recommended that:

17. A review of the fees for access to health information records should be deferred to the Regulation Review in 2005.

Stakeholders were asked to consider the individual's right to access the individual's own information within the electronic health record. In particular, they were asked whether HIA needs amendment to address the concept of custody or control within the provincial electronic health record. There was not consensus among stakeholders who commented about the need for changes or about what changes might be appropriate. Although the Committee noted that the provincial electronic health record is still in the early stages of its evolution, it concluded that further review of the need for clarity and transparency is warranted.

(Reference consultation question 14 in Appendix C)

The Committee recommended that:

18. A committee of the Legislature established early in 2005 should consider the need for more clear and transparent rules for the electronic health record.

Although not directly related to the concept of custody and control, a unique health service provider identifier is required to allow for authorization and authentication of those who access and enter information into the provincial electronic health record.

(Reference consultation question 14 in Appendix C)

The Committee recommended that:

19. A provision should be added to HIA to allow for the collection, use and disclosure of a unique identifier for health service providers for authorization and authentication purposes in the electronic health record.

COLLECTION OF HEALTH INFORMATION

The *Health Information Act* protects the individual's privacy by limiting the collection of individually identifying health information. The Act requires information to be collected directly from the individual except in circumstances set out in the Act.

There was general consensus among stakeholders who commented that this requirement is appropriate as written, supporting both custodian needs and individual rights. A question was raised about collection in the electronic environment. Legal review indicates the Act already permits custodians to indirectly collect a wide range of information that is necessary to provide health services. Alberta Health and Wellness will provide clarification of this authority in the "Guidelines and Practices Manual".

(Reference consultation question 15 in Appendix C)

The Committee recommended that:

20. No changes are required to the duty to collect health information directly from the individual except as authorized.

The Canadian Blood Services requested authorization of indirect collection for public health purposes. This need is currently addressed by the provision allowing indirect collection where direct collection would prejudice the safety of any other person. The Committee recognizes the importance of public health and believes the matter requires further consideration.

(Reference consultation question 15 in Appendix C)

The Committee recommended that:

21. Provisions respecting collection of health information for public health purposes should be considered by a committee of the Legislature early in 2005 when additional health service providers are considered for inclusion within the scope of the *Health Information Act*.

Stakeholders were asked whether custodians should be permitted to collect information about the individual's family health history without the consent of the family members where necessary to provide health care to the

individual. The general consensus was that collection of family history without consent is essential to provide timely, efficient patient treatment and care, and that current provisions are appropriate.

(Reference consultation question 16 in Appendix C)

The Committee recommended that:

22. Provisions respecting the collection of information about the individual's family health history without the consent of family members should not be amended.

The *Health Information Act* requires custodians to take reasonable steps to inform the individual of the purpose and legal authority for the collection of information. It also requires the custodian to provide contact information for a person to answer questions about the collection.

Stakeholders who commented are somewhat divided on whether the requirement is effective, and about what methods are most appropriate. However, the majority of those who responded to the question believe it is effective. The Committee recognized that this matter relates to the pan-Canadian health information privacy and confidentiality framework. Because the framework is still in draft form and subject to change based on the consultations currently underway, the Committee was not in a position to assess the degree of harmonization between these provisions and the framework.

(Reference consultation question 17 in Appendix C)

The Committee recommended that:

23. The duty to inform individuals about information collection practices should be reviewed by a committee of the Legislature early in 2005 when the pan-Canadian health information privacy and confidentiality framework is finalized.

USE OF HEALTH INFORMATION

All custodians under the *Health Information Act* are mandated to use health information (including registration information; diagnostic, treatment and care information; and health service provider information) to fulfill their responsibilities in the health system, including use to:

- Provide health services
- Determine an individual's eligibility to obtain health services
- Investigate, review or inspect the services provided by health service providers
- Conduct research into better health practices,

services or management
- Provide health service provider education
- Carry out the specific purposes in other legislation such as the *Hospitals Act*, the *Public Health Act*, the *Cancer Programs Act* and the *Regional Health Authorities Act*
- Manage internal operations such as planning, allocating resources, quality improvement, evaluation, obtaining payment for services

Some custodians have broader regional or provincial responsibilities (e.g. the Minister and Alberta Health and Wellness, RHAs and the Alberta Cancer Board) and are authorized to use health information to:

- Plan and allocate resources
- Manage the health system
- Conduct public health surveillance
- Develop health policies and programs

Custodians are allowed to use health information because they must be able to assess the outcomes of their actions, provide quality health services and meet other expectations. The concept of "controlled sharing" under the Act allows custodians to obtain and use the amount of health information in the form necessary to perform their duties. This includes the use of individually identifying health information without consent if it is necessary for the purpose.

Stakeholders were asked whether the current list of purposes in the Act is appropriate for existing custodians and for potential new custodians, whether it is appropriate to use identifying health information without consent for the authorized purposes, and whether the list of authorized uses should be expanded, restricted or modified.

With the exception of the Alberta Medical Association (AMA), stakeholders who commented on the question generally agree with the current list of purposes for which health information may be used without consent, and some would expand the list. Suggestions to add fund raising and to broaden the authorized use for "health service provider education" to "education" were seen by the Committee to shift the balance too far away from protection of privacy.

The AMA continues to object to use or disclosure without consent for anything other than care and treatment, and argues identifiable health information is not required for policy development, planning, resource allocation, health system management and public health surveillance purposes. While the Committee acknowledged the AMA's concerns, it accepted the argument that such information must be collected in identifiable form so that it can be analyzed and aggregated for use in statistical form to plan and manage the health system. HIA requires custodians to apply the principle of least amount of information and highest level of anonymity in its use of information. In addition, custodians have many measures in place to restrict access to databases containing identifiable information, and to protect privacy and confidentiality.

Stakeholders saw a need to reflect the mandates of additional custodians if private sector providers or new types of entities are brought within the scope of the Act. A number of specific suggestions were made including a request for public health and statistical analysis involving data matching as an authorized use. The suggestions can be considered as part of the investigation of scope changes through the proposed committee of the Legislature early in 2005.

(Reference consultation questions 18, 20 and 21 in Appendix C)

The Committee recommended that:

24. No changes are required to the current list of purposes for the use of individually identifying health information without consent.

(Reference consultation question 19 in Appendix C)

25. The new committee of the Legislature should consider the list of authorized purposes for the use of identifying health information when it reviews the addition of health service providers and health service organizations early in 2005.

ELEMENTS OF CONSENT

The Act authorizes custodians to disclose health information with the consent of the individual. Consent must be provided in writing or electronically and specify:

- Who is to receive the information and why
- The effective dates of the consent
- Specifics about what information is to be disclosed
- An indication the individual has been made aware of the reasons why the information is needed
- Implications to the individual of consenting or refusing to consent

Most of the stakeholders who commented saw the elements of consent as appropriate, but some of these had reservations about the requirements being burdensome or difficult to manage where individuals lack the mental capacity to consent. Those who were not in support saw the requirements as too detailed or onerous.

Stakeholders were also asked to comment on whether verbal consent should be allowed. Most of those who commented said verbal consent should be allowed in at least some circumstances, but half of these support recording the verbal consent.

The nature of the consent requirement is addressed in the pan-Canadian information privacy and confidentiality framework. Since the framework is still in draft form and subject to change following consultation, the Committee cannot advise on the matter of harmonization of rules.

(Reference consultation question 22 in Appendix C)

The Committee recommended that:

26. A committee of the Legislature should consider the matter of consent in early 2005 when the pan-Canadian health information privacy and confidentiality framework is finalized.

DISCRETIONARY DISCLOSURES WITHOUT CONSENT

The Act permits custodians to disclose diagnostic, treatment and care information without consent in specific circumstances, subject to the overriding principles of least amount of information at the highest level of anonymity. These discretionary disclosures include disclosures to:

- Another custodian for any of the authorized purposes for use of health information (as described in a previous section of this report)
- Family members or others with a close personal relationship, if the information is given in general terms and concerns the presence, location, condition, diagnosis and prognosis and is not contrary to the express request of the individual
- A committee for quality assurance
- Any person to avert or minimize imminent danger to health or safety of any person
- Anyone to whom the disclosure is authorized or required by an enactment of Alberta or Canada

Stakeholders were asked whether the discretionary disclosures without consent are reasonable and appropriate, and whether they should be restricted in any way. A minority of those who responded agreed the

current list is reasonable and appropriate. Several organizations made specific suggestions to enable additional discretionary disclosures. The Committee considered the suggestions and supported only a limited number of additions. Some of those not supported by the Committee are already authorized; some were seen to shift the balance too far from privacy protections and others to require additional consultation.

Some stakeholders suggested changes to restrict current discretionary disclosures. The Committee did not agree with suggested restrictions, in some cases because the disclosures are necessary for the health system to function.

(Reference consultation question 23 in Appendix C)

The Committee recommended that:

27. The Act should be amended to allow for disclosure of individually identifiable diagnostic, treatment and care information without consent to:

- **Health departments of provincial, territorial and federal governments for health services provided to persons under their jurisdiction**
- **Alberta government departments or federal government departments for determining eligibility to receive a health service or a health-related service or benefit, or for payment purposes**
- **Third parties for payment purposes**
- **A successor where the custodian remains a custodian but transfers records**
- **First Nations police services on the same basis as permitted to other police services.**

(Reference consultation question 23 in Appendix C)

28. The Act should be amended for consistency with the *Health Professions Act* to authorize professional bodies to retain health information used in an investigation or a hearing for ten years instead of destroying the information at the earliest opportunity.

(Reference consultation question 23 in Appendix C)

29. The Act should not be amended to authorize disclosure of individually identifiable diagnostic, treatment and care information without consent to:

- **Collaborative or integrated programs**
- **The Canadian Medical Protective Association for medical-legal purposes**
- **The clergy or to "any person", the presence and location of an individual in a health facility**

- **Any person to address a complaint or allegation made in a public forum.**

(Reference consultation question 23 in Appendix C)

30. The Act should not be amended to:

- **Remove ability to disclose to the Chief Electoral Officer**
- **Restrict disclosure without consent to purposes related to direct care and treatment**
- **Require the individual to be notified before disclosure without consent**
- **Allow disclosure of psychological raw test and data scores only to those qualified to interpret them.**

DISCLOSURE TO POLICE SERVICES

The *Health Information Act* allows custodians to disclose diagnostic, treatment and care information:

- Pursuant to a subpoena, warrant or court order
- To a municipal or provincial police service to investigate an offence involving a life-threatening personal injury to the individual unless disclosure is contrary to the express request of the individual
- To minimize an imminent danger

Some police services have suggested these discretionary disclosures to police are too restrictive and do not permit police services to obtain necessary health information in a timely manner. The challenge is to ensure the appropriate balance between the privacy rights of the individual seeking care and treatment and the police requirements for personal health information.

Stakeholders were asked whether discretionary authority to disclose to police services without consent should be extended to disclose registration information for purposes of obtaining a warrant, subpoena or court order. Slightly less than half the respondents recommended no change. The remainder (including the police) agreed with providing at least some discretionary authority, in certain circumstances, to disclose registration information to police.

Stakeholders were not always clear, nor in agreement on the circumstances under which greater disclosure would be appropriate. The Alberta College of Pharmacists suggested a provision that would allow pharmacists to provide individually identifying health information to the police when they have reasonable grounds to believe a

crime has been committed or is being attempted in relation to a prescription for medication. The Pharmacists Association of Alberta supported the suggestion, as did some other pharmacy-related stakeholders.

Some stakeholders were concerned that extending the provisions for disclosure to police without consent may discourage patients from seeking medical care or may result in individuals withholding information necessary to provide treatment and care.

In both the written and oral presentations on this subject, there was frequent reference to the term "registration information". Under the Act, registration information includes elements such as name, personal health number, gender, date of birth, home address, health service eligibility information, location information and billing information.

However, the submissions and oral presentation indicate the police are also seeking other types of health information. Their requests included:

- Registration information including the individual's location in a facility and admission and discharge dates. It is questionable whether, under the circumstances outlined by the police, location in a hospital or admission information would constitute "registration information" since it could reveal specific information about the health of the individual
- Diagnostic, treatment and care information, including where and when a person was treated, the nature of the injuries, and what treatment and procedures were carried out
- Health service provider information, specifically, the name, address and telephone number of the physician providing treatment, in order to determine where health records may be located, or to identify another potential source of information

A number of amendments were requested by police services, including:

- Disclosure of registration, and in some cases, diagnostic treatment and care information to police seeking a warrant, subpoena or court order
- Disclosure of health information to a law enforcement agency for the purpose of assisting in the investigation of a criminal or provincial offence

and satisfying their duties under the Criminal Code of Canada
- To encourage or mandate health care workers to notify the police when they treat a person whose injuries were caused in the commission of a crime

The Committee noted that any expansion of mandatory or discretionary disclosure of health information to the police could result in challenges to the *Canadian Charter of Rights and Freedoms*.

The Committee considered a number of options including maintaining the status quo. The Committee decided the current provisions do not allow the police adequate access to health information to allow them to carry out their duty to enforce the law.

(Reference consultation question 24 in Appendix C)

The Committee recommended that:

31. The Act should be amended to mandate disclosure, without consent, to police services of:

- **Patient name**
- **Address/location in facility**
- **Date of admission**
- **Name of physician**
- **Nature of injury**

When:

- **For purposes of obtaining a warrant or subpoena, and when the police have reasonable grounds to suspect that the person seeking health services has been involved in some form of criminal activity; and make a request for that information, or**
- **A custodian has reasonable grounds to suspect that the person seeking health services has been involved in some form of criminal activity**

(Reference consultation question 24 in Appendix C)

32. The Act should be amended to mandate disclosure of limited health information without consent to police services where a custodian has reasonable grounds to suspect a prescription reveals or tends to reveal that an offence has been committed or is being attempted, including the individual's name, address, date of birth, personal health number, the drug, dosage, prescriber's name and address, a copy of the prescription, and any other health information contained on the prescription.

(Reference consultation question 24 in Appendix C)

33. The Government of Alberta should consider introducing separate stand-alone legislation requiring mandatory reporting by custodians to police services of gunshot wounds, stabbings and severe beatings.

(Reference consultation question 24 in Appendix C)

34. The Act should be amended to allow the disclosure of health information, without consent, by Alberta Health and Wellness or other custodians to police services where there is reason to believe that an individual has committed fraud in obtaining Alberta health care insurance coverage, health services or health benefits from the publicly funded health system.

TRIPLICATE PRESCRIPTION PROGRAM

The Triplicate Prescription Program was established in 1986 to monitor prescribing and dispensing practices related to a select group of narcotic and controlled drugs with a high potential for divergence for illicit purposes. Participation in the program is mandatory for physicians and pharmacists. Prescriptions for these drugs are written in triplicate. The physician who prescribes the drug retains one copy. The second and third copies are given to the patient who presents them to the pharmacy. The pharmacist retains a copy and sends a copy to the College of Physicians and Surgeons for inclusion in the program database for monitoring and analysis.

The policy position is that HIA authorizes disclosures of this type. However, to remove any doubt, a specific provision authorizing disclosures for purposes of the Triplicate Prescription Program was proposed in the Consultation Guide. There was no opposition to this proposal.

(Reference consultation question 25 in Appendix C)

The Committee recommended that:

35. The Act should be amended to provide explicit authority for the Triplicate Prescription Program.

GENETIC INFORMATION

Genetic information is generally seen in the same light as health information but more fundamentally personal given the potential of discrimination based on genetic characteristics. Technological advances in genetic testing and use of the information is evolving and further analysis is required of what, if any, unique attributes of genetic information require different rules for privacy and confidentiality.

Stakeholders were asked whether stronger provisions were required to protect the confidentiality of genetic information. Slightly less than half of those who responded to the question were opposed to stronger provisions to protect genetic information as they felt this information is no more or less confidential than health information generally. About a quarter of commentators suggested genetic information be specifically referenced or defined in the Act. Another quarter of stakeholders suggested a need to prohibit disclosure of genetic information without individual consent.

The Committee noted that this matter is to be addressed in the pan-Canadian framework on privacy and confidentiality of health information. Since the framework is not finalized, the Committee was not able to deal with the question of harmonization between HIA and the framework.

(Reference consultation questions 2 and 26 in Appendix C)

The Committee recommended that:

36. Provisions respecting genetic information should be considered by a committee of the Legislature in early 2005 when the pan-Canadian health information privacy and confidentiality framework is finalized.

INFORMED KNOWLEDGEABLE IMPLIED CONSENT

Under the *Health Information Act*, a custodian may collect, use and disclose individually identifying diagnostic, treatment and care information without the consent of the individual for care and treatment. This authority is subject to the overriding principles that restrict the flow of information: least amount of information and highest level of anonymity necessary for the purpose.

The individual does not have the ability to consent or withdraw consent for disclosures of information required for care and treatment, although the custodian is required to consider the individual's expressed wishes in deciding how much information to disclose. The Act reflects the practice that was in place in the health sector at the time it was drafted.

Since that time, the federal *Personal Information Protection and Electronic Documents Act* (PIPEDA) has come into effect and applies to custodians such as pharmacies, pharmacists and physicians in private practice. Under PIPEDA, Industry Canada indicates that implied informed consent is appropriate within the "circle of care". This differs from the approach in HIA described

above. PIPEDA will apply unless the federal government exempts a province from the application of PIPEDA on the basis that the province has enacted legislation substantially similar to PIPEDA.

Stakeholders were asked whether an informed knowledgeable implied consent model for disclosures for care and treatment is appropriate for Alberta's health system. A third of the stakeholders who commented supported the informed knowledgeable implied consent model, another third did not support the model, and the final third appeared to be in support but were somewhat equivocal.

The Committee noted the matter of informed implied consent is central to the pan-Canadian health information privacy and confidentiality framework. Since the pan-Canadian framework is not yet finalized, the Committee was not in a position to address the matter of harmonization.

(Reference consultation question 27 in Appendix C)

The Committee recommended that:

37. A committee of the Legislature should review consent requirements under the *Health Information Act* in early 2005 when the pan-Canadian health information privacy and confidentiality framework is finalized.

DISCLOSURES FOR RESEARCH PURPOSES

Under the *Health Information Act*, custodians may decide to disclose individually identifying registration, diagnostic, treatment and care information for research purposes after an ethics committee determines that consent is not required. Consent is always required when the researcher will contact individuals for additional information.

Policy established by the health, natural and social sciences research granting agencies guides the establishment of research ethics boards by institutions that wish to conduct research. Research ethics boards must then be designated in the HIA regulations in order to fulfill the responsibilities of an ethics committee under the HIA.

Custodians are required under HIA to consider whether aggregate or anonymous information would be adequate for the purpose (highest level of anonymity) and disclose the least amount of information essential for the purpose. This minimizes risk to individual privacy and confidentiality of information.

The researcher must agree to the terms of an agreement with the custodian in accordance with HIA before the health information may be disclosed.

Stakeholders were asked whether the research provision in the Act is reasonable, effective and operationally effective. Eighteen stakeholders commented. RHAs were generally satisfied with the research provisions, though one acknowledged potential burdens for researchers and custodians. There was relatively little overlap of suggestions for change, but a significant portion dealt with the research ethics boards. Other suggestions dealt with matters of consent and surrogates, new restrictions on commercial research, management of aggregate databases in the public interest, discontinuation of the requirement to disclose the least amount of information at the highest level of anonymity and clarification of various provisions.

The Health Quality Council of Alberta and the Canadian Institute for Health Information (CIHI) recommended their mandates be reflected in the Act. CIHI suggested designation of bodies to collect and analyze health information for purposes of health system management and research, and explicit authority enabling disclosure of defined data sets for these purposes.

(Reference consultation questions 3 and 28 in Appendix C)

The Committee recommended that:

38. A committee of the Legislature established early in 2005 should consider a new category of entity under the Act with a limited defined mandate to receive identifiable information for statistical analysis and research.

(Reference consultation questions 2 and 28 in Appendix C)

39. The term "ethics committee" should be changed to "research ethics board"

(Reference consultation question 28 in Appendix C)

40. The Information and Privacy Commissioner should be authorized to publish ethics committee research approvals on a website with an explanatory note that the research has not necessarily been conducted and that health information has not necessarily been disclosed.

(Reference consultation questions 2 and 28 in Appendix C)

41. No changes should be made to ethics committee duties, composition or number; consent requirements and surrogates; requests for clarification or the requirement to consider the least amount of information and highest level of anonymity for the research purpose.

DUTIES AND OBLIGATIONS TO CUSTODIANS

The *Health Information Act* includes clear and stringent duties and obligations on the custodian to protect the confidentiality of the individual's personal health information. Rules are included respecting physical, technical and security safeguards, privacy impact assessments, information managers and data matching. Stakeholders were asked whether the duties and obligations on the custodian are appropriate and reasonable.

Although two stakeholders noted that the duties and obligations of custodians are reasonable, there were issues around the administrative burden imposed by some requirements and questions about whether the resources devoted to compliance were sufficiently justified by the privacy and access benefits gained by Albertans.

Particular areas of concern included keeping records of disclosures without consent, providing notification to non-custodian recipients of disclosures of the purpose and authority for the disclosure, and privacy impact assessment requirements. Custodian obligations in relation to affiliates were a concern. Clarification was requested about information managers, information management agreements, custodians who are information managers, and relationships with affiliates. Many of these matters were raised in the context of the provincial electronic health record and other electronic data systems.

The Committee noted that additional information gathering and analysis is required before recommendations can be made about future legislative requirements related to the provincial electronic health record. In the meantime these matters can be addressed through existing legislation, guidelines and interpretations.

(Reference consultation questions 2, 14 and 29 in Appendix C)

The Committee recommended that:

42. Alberta Health and Wellness consider the need for information manager provisions, information manager agreements, application of these provisions to custodians who are also information managers and the relationship between information manager provisions and affiliate provisions prior to the next full review of the Act by a committee of the Legislature.

With regard to the requirement to note disclosures and retain the notation for ten years, the Committee noted that elimination of the notation requirements would remove the ability of individuals to know to whom records were disclosed without consent. It recognized a concern about the length of retention of the notation requirement, but concluded further research was needed about an appropriate retention period for all custodians. The Committee also heard that the requirement to note the purpose of every disclosure was not feasible where disclosure is from the electronic health record or another electronic system, or part of a batch process. However, in electronic systems with automated audit capability, the system can produce a log of every disclosure, including the information disclosed, person disclosing and date of disclosure.

The only requirement that cannot be met is the purpose of the disclosure.

(Reference consultation question 29 in Appendix C)

The Committee recommended that:

43. The requirement to note every disclosure of individually identifiable health information without consent should be retained and amended to not require notation of the purpose of the disclosure when the disclosure is made electronically through a system with automated audit capability.

(Reference consultation question 29 in Appendix C)

44. Alberta Health and Wellness should consult with stakeholders about the required period of retention for disclosure notations prior to the next full review of the Act by a committee of the Legislature.

The Act currently requires written notification to a recipient outside the "controlled arena" of diagnostic, treatment and care information specifying the purpose and authority for the disclosure. The written notification serves as a notation on the patient record of the disclosure and provides protection for the custodian in demonstrating the disclosure is authorized by the Act. Suggestion was made to eliminate the requirement, or at least to eliminate the requirement when the information is provided to the individual the information is about, and the disclosure is not in response to a formal request for access by the individual.

(Reference consultation questions 22 and 29 in Appendix C)

The Committee recommended that:

45. The requirement for written notification to the recipient of the purpose and authority for disclosure of diagnostic, treatment and care

records should be retained, but amended to make explicit that the requirement does not apply where the disclosure is to the individual the information is about, and the disclosure is not in response to a formal application for access by the individual.

The Committee considered several other suggestions and concluded no other changes should be made to custodian duties and obligations.

(Reference consultation question 29 in Appendix C)

The Committee recommended that:

46. No changes should be made to provisions respecting custodian duties in relation to affiliates, duties to protect health information outside Alberta, data matching, collection of the least amount of information necessary for the purpose, and privacy impact assessments.

THE COMMISSIONER

The sections of the *Health Information Act* dealing with the Commissioner ensure there is clear and explicit authority for effective oversight of administration of the Act, and redress where the Act is not properly administered. Under the Act, the individual has the right to ask the Commissioner to review any decision, act or failure to act, of the custodian in relation to a request for access, correction or amendment. Individuals may also request a review of any collection, use or disclosure believed to be in contravention of the Act.

Stakeholders were asked if they had any changes to suggest. The Information and Privacy Commissioner suggested the Commissioner be explicitly authorized to conduct audits and compel information for an audit.

Alberta Health and Wellness and the RHAs are already subject to audit by the Auditor General, and additional audit powers may have implications for custodians. The Committee noted that stakeholders have not been consulted about the suggestion.

(Reference consultation question 30 in Appendix C)

The Committee recommended that:

47. A committee of the Legislature established early in 2005 should consider the Information and Privacy Commissioner's request for explicit powers to audit and compel information for an audit.

The Commissioner also suggested explicit powers to enter into extra-provincial agreements and to consult and

delegate extra-provincially. These powers are intended to be used where more than one jurisdiction may be involved in investigation of the same matter. The Committee noted a need for additional information about the way these matters would be handled when the provisions of Alberta legislation differ from provisions in other jurisdictions, and about how the privacy of Albertans and the confidentiality of their information would be protected.

(Reference consultation question 30 in Appendix C)

The Committee recommended that:

48. A committee of the Legislature should consider the Information and Privacy Commissioner's request for explicit powers to enter into extra-provincial agreements and to consult and delegate extra-provincially in 2005.

Two different suggestions were made about ways to deal with "orphan records". These are health records that a custodian is unable or unwilling to continue to protect and make accessible to the individuals the records are about. This can occur when a custodian dies, ceases to practice or leaves the province. The Committee noted that any solution will affect all custodians, and that custodians have not yet been consulted about possible solutions.

The College of Physicians and Surgeons suggested that the Commissioner be given authority and responsibility to take custody of, or seize orphan records and administer them. The Commissioner suggested another approach which would place continuing responsibility on the custodian (or the custodian's estate) for health information when the custodian ceases to practice.

(Reference consultation questions 2 and 30 in Appendix C)

The Committee recommended that:

49. A committee of the Legislature should consider the matter of "orphan records" in 2005.

The Committee considered a number of other suggestions including a penalty for making repeated requests judged by the Commissioner to be vexatious, extension of the Commissioner's powers to include all entities with health information, power to rule on miscarriage of justice, changes to the privacy impact assessment process and release of the name of an affiliate who discloses a breach by a custodian to the Commissioner. The Committee did not agree with the suggestions.

(Reference consultation question 30 in Appendix C)

The Committee recommended that:

50. The Act should not be amended to include a penalty for making repeated requests judged by the Commissioner to be vexatious, to extend the Commissioner's powers to include all entities with health information, to add a power to rule on miscarriage of justice, to deal with the process for privacy impact assessments, or to allow for release of the name of an affiliate who discloses a breach by a custodian to the Commissioner.

The Committee also considered a suggestion to change the provisions relating to the duty to comply with an order when the order is under review by the Courts. The Committee noted that these provisions are currently harmonized with FOIP and PIPA, and concluded that no changes should be made.

(Reference consultation question 30 in Appendix C)

The Committee recommended that:

51. The Duty to Comply with Order provisions of the Act should not be amended.

SUBSTITUTE DECISION-MAKERS

The Act includes provisions to ensure that another person can exercise the rights or powers of an individual under the Act in specific circumstances. These include:

- Guardians may act on behalf of persons under the age of 18 that do not understand the nature and consequences of a decision
- Guardians and trustees appointed for an individual under the *Dependent Adults Act*
- Agents designated for an individual under a personal directive under the *Personal Directives Act*
- Persons granted power of attorney by the individual
- "Nearest relatives" for formal patients under the *Mental Health Act*
- Any person with written authorization from the individual

Although a few suggestions were made to provide for substitute decision-makers, most of these are already covered in the Act. These include family members and disclosures without consent if in the opinion of the custodian; disclosure is in the best interest of the individual. However, the *Alberta Rules of Court* (Regulation 390/68) permit a next friend or guardian ad litem to represent infants or adults of unsound mind in

litigation proceedings in certain circumstances. There is currently no authority for next friends or guardian ad litems to access or disclose health information on behalf of individuals they are representing in litigation.

(Reference consultation question 31 in Appendix C)

The Committee recommended that:

52. The Act should be amended to provide a limited authority for a "next friend" or guardian ad litem to exercise the rights or powers of the individual where the exercise relates to the powers and duties of the next friend or guardian ad litem.

The Alberta Long Term Care Association proposed extensive specific provisions to provide for substitute decision-makers where the individual does not have the ability to name a substitute decision-maker and where a relative or friend is willing to assume responsibility but is not prepared or able to pursue the formal processes under other legislation. The Committee acknowledged the importance of the matter in the long term care environment, especially in light of growing numbers of individuals in older age groups affected by Alzheimer's and related disorders. The Committee also recognized the complexities of a new substitute decision-making scheme and the difficulties that can occur as families attempt to deal with these situations.

(Reference consultation question 31 in Appendix C)

The Committee recommended that:

53. Alberta Health and Wellness should review the matter of substitute decision-makers for consideration by a committee of the Legislature during the next full review of the Act.

OFFENCES AND PENALTIES

The *Health Information Act* provides for penalties when a custodian or any other person commits an offence under the Act.

Most stakeholders who responded to a question about the appropriateness of the offences and penalties saw them as appropriate. However, a number of suggestions were made, including: a cap on the aggregate amount of fines in a year, higher fines and protection from fines on a custodian in relation to an action by an affiliate.

No fines have been imposed since the Act was proclaimed, providing no evidence of need for higher fines, a cap on fines or protection from fines. Other privacy statutes (such as FOIP, PIPA and PIPEDA) do not provide for caps on fines. The Committee concluded

that current provisions appear to provide both sufficient deterrence against offences and protection to those who act in good faith but unknowingly contravene the Act.

Clarification was suggested regarding when fines will be imposed for violation and whether fines can be imposed on an employee of a custodian. However, the Act is clear about its application and clarification can be provided in guidelines. Clarity was requested about the line between marketing for commercial purpose and continuing care and treatment. Professionals may seek advice initially from their professional colleges for guidance as to what constitutes professional practice.

(Reference consultation question 32 in Appendix C)

The Committee recommended that:

54. The offences and penalties under the Act should not be amended.

REGULATIONS

Stakeholders were asked whether they had suggestions for improvement on the rules contained within the Regulations under HIA. Among other things, the Regulations currently include:

- The list of research ethics boards designated as ethics committees for purposes of the Act
- The list of panels, committees, board and individuals designated as custodians
- Details on the definition of registration information
- Rules for ensuring administrative, technical and security safeguards

Seven organizations commented. Three housekeeping updates were suggested, and accepted by the Committee.

(Reference consultation question 33 in Appendix C)

The Committee recommended that:

55. The Health Information Regulation should be updated to:

- **Delete s. 1(2), and the reference in s. 6(2) to the repealed HIA s.59**
- **Replace in s. 2(b) the "Billing Practice Advisory Committee" with "a committee of an organization referred to in s. 18(4) of the *Alberta Health Care Insurance Act*."**
- **Replace the reference to the *Child Welfare Act* in s. 4 to the *Child, Youth and Family Enhancement Act* when it comes into force.**

The Committee considered but did not agree with the suggested deletion of the requirements for a written agreement respecting information to be stored, used or disclosed outside Alberta.

(Reference consultation question 33 in Appendix C)

The Committee recommended that:

56. The requirements in the regulation specifying matters to be addressed in a written agreement respecting information to be stored, used or disclosed outside Alberta should be retained.

The Committee considered suggested additions to the regulations. It agreed a regulation should be developed respecting retention, disposal and archival storage of records. It also considered a suggestion that principles for technical, physical or administrative security be added to the regulation. It noted that guidance is currently contained in the HIA "Guidelines and Practices Manual", and that a step-by-step assessment guide is available on the Information and Privacy Commissioner's website. The Committee determined the matter should be deferred for consideration in the 2005 Regulation Review.

(Reference consultation question 33 in Appendix C)

The Committee recommended that:

57. Alberta Health and Wellness should consult with stakeholders and develop a regulation respecting retention, disposal and archival storage of records as part of the review of the regulation in 2005.

(Reference consultation question 33 in Appendix C)

58. Alberta Health and Wellness should consult with stakeholders to determine whether principles for technical, physical or administrative security should be added to the regulation in 2005.

Other suggestions for new regulations included reference to the *Electronic Transactions Act*, and addition of a regulation respecting the scope and content of information manager agreements. The Committee determined that reference to the *Electronic Transactions Act* (ETA) is not required. Because the ETA applies to health information under HIA unless a matter is specifically exempted from application of the ETA. Electronic transactions are allowed, provided that HIA's privacy, confidentiality and access rules are adhered.

With regard to the information manager agreements, the Committee determined that the content of these agreements is specified in guidelines. Since this area is continuing to evolve, the Committee concluded the matter is best not included in regulations at this time. However, the regulation-making power should be retained for potential future use.

(Reference consultation question 33 in Appendix C)

The Committee recommended that:

59. The Health Information Regulation should not be amended to include reference to the *Electronic Transactions Act* or to include the scope and content of information manager agreements.

APPENDICES

Appendix A: Written Submissions to the Review Committee

1. IMS Health, Canada
   Mr. Brian Carter, Director - Corporate Affairs

2. Municipal District of Greenview No. 16
   Mr. Tony Yelenik, Reeve

3. County of Warner No. 5
   Mr. Allan Romeril, Administrator

4. City of Edmonton Emergency Response Department
   Dr. Sunil M. Sookram, MD, FRCPC

5. The Better Business Bureau of Southern Alberta
   Ms Ellen Wright, President and CEO

6. Edmonton Emergency Response Department
   Mr. Steve Rapanos, Chief - Emergency Medical Services

7. Municipal District of Bonnyville No. 87
   Mr. R.A. Doonanco, Municipal Manager

8. County of Minburn No. 27
   Mr. Ross Warren, EMT-A, Director of Protective Services/Fire Chief

9. Petro-Canada
   Ms Greta Raymond, Chief Privacy Officer

10. Edmonton Police Service
    Mr. Mike Bradshaw, Acting Chief of Police

11. Private Submission
    Ms Dorene A. Rew

12. Lethbridge Regional Police Service
    Staff Sergeant Jeff Cove

13. Dovetail Partners, Management Consulting
    Mr. Merv Manthey, CMC

14. Village of Onoway
    Ms Hazel Bourke, Mayor

15. County of Vermilion River #24
    Ms Glenda Thomas, County Administrator

16. County of Athabasca No. 12
    Mr. Jim Woodward, County Manager

17. Town of Innisfail
    Mr. Dale P. Mather, CLGM - Chief Administrative Officer

18. Consumers' Association of Canada (Alberta)
    Mr. Larry Phillips, President and Members of the Board

19. Village of Thorsby
    Mr. Norman Osness, Acting Mayor

20. Calgary Chamber of Commerce
    Ms Carol Demong, Chair - Health Care Committee

21. Workers' Compensation Board of Alberta
    Mr. Guy R. Kerr, President and CEO

22. Woodlands County
    Mr. Luc Mercier, CAO

23. Alberta Heritage Foundation for Medical Research
    Dr. Kevin Keough, PhD - President and CEO

24. Alberta Blue Cross
    Mr. Nicholas O. Arscott, Vice-President - Benefit Services

25. Canadian Federation of Independent Business
    Ms Corinne Pohlmann, Director of Provincial Affairs - Alberta/NWT

26. Workplace Health International
    Ms Lynn Rogers, RN, MN, OHNC - President

27. The Law Society of Alberta
    Mr. Donald F. Thompson, Q.C. - Executive Director

28. Canadian Life and Health Insurance Association Inc.
    Mr. Frank Zinatelli, Vice President and Associate General Counsel

29. Insurance Bureau of Canada
    Mr. Jim Rivait, Vice-President - Prairies, NWT and Nunavut

30. Private Submission
    Mr. Robert Hyland

31. City of Edmonton
    Mr. David Edey, City Clerk

32. Alberta Mental Health Board
    Mr. Ray Block, CEO

33. Aspen Regional Health Authority
    Mr. Troy Shostak, Manager - Information Access and Privacy

34. Pharmacists Association of Alberta
    Mr. Barry Cavanaugh, CEO

35. Health Quality Council of Alberta
    Dr. John Cowell, CEO

36. College of Physicians and Surgeons of Alberta
    Mr. John Swiniarski, MBA - Assistant Registrar

37. Alberta College of Pharmacists
    Mr. Greg Eberhart, Bsc Pharm; CAE - Registrar

38. Capital Health
    Ms Sheila Weatherill, President and CEO

39. Independent Insurance Brokers Association Alberta
    Mr. Harold Baker, CEO

40. Office of the Information and Privacy Commissioner
    Mr. Frank Work, Q.C. - Information and Privacy Commissioner

41. Edmonton Chamber of Commerce
    Mr. Paul Byrne, Chair and Mr. Martin Salloum, President and CEO

42. Alberta Association of Registered Nurses
    Ms Jeanne Besner, President

43. Canadian Association of Chain Drug Stores
    Ms Lori Turik, Vice-President - Public Policy

44. Calgary Health Region

45. The Provincial Diversion Program Advisory Committee
    Ms Laurie Beverley, Executive Director - Programs and Research

46. Calgary Police Service
    Mr. Jack Beaton, Chief of Police

47. Alberta Medical Association
    Dr. Jane Ballantine, President

48. Beaver County
    Ms Margaret Jones, CAO

49. Canadian Mental Health Association
    Mr. Aleck Trawick, Executive Vice-President and
    Chair, CMHA/HIA Review Task Group

50. College of Physical Therapists of Alberta
    Ms Sue Turner, Registrar

51. Value Drug Mart Associates Ltd.
    Mr. Jody Shkrobot, Bsc Pharm - Manager, Pharmacy Services and Professional Affairs

52. University of Calgary and University of Alberta
    Ms Jo-Ann Munn Gafuik - University of Calgary and
    Mr. Gordon Unger - University of Alberta

53. Alberta Cancer Board
    Ms Suzanne Vorvis, Manager - Information Security and Privacy

54. Alberta Shock Trauma Air Rescue Society (STARS)
    Ms Linda J. Powell, Executive Administrator and Privacy Officer

55. Town of Whitecourt
    Mr. Dean Bradford, Town Manager

56. Town of Cochrane
    Ms Judy Stewart, Mayor

57. Town of Canmore
    Mr. Bertram Dyck, CAO

58. East Central Health
    Mr. Steve Petz, President and CEO

59. Faculty of Medicine - University of Calgary
    Dr. Ian Mitchell, Professor - Department of Paediatrics and Director - Office of Medical Bioethics

60. Health Boards of Alberta
    Ms Jean Graham, Chair

61. The Canadian Medical Protective Association
    Dr. John E. Gray, Executive Director/CEO

62. Private Submission
    Ms Shirley Bague

63. Canadian Institute for Health Information
    Ms Glenda Yeates, President and CEO

64. Alberta Long Term Care Association
    Ms Dianne Nielsen, Executive Director

65. Syncrude Canada Ltd.
    Mr. Jerry Handford, General Manager - Human Resources

66. Canadian Institutes of Health Research
    Ms Patricia Kosseim, Interim Director - Ethics Office

67. Government of Alberta
    Dr. Roger Palmer, Deputy Minister - Alberta Health and Wellness

68. Chabad Lubavitch of Edmonton
    Rabbi Ari Drelich

69. Alberta Occupational Health Nurses Association
    Mr. Terry MacDonald, RN OHNC - Provincial President

70. Alberta Urban Municipalities Association
    Mayor E.R. (Ernie) Patterson, President

71. Alberta Health Facilities Review Committee
    Mr. Bob Maskell, MLA - Chair

72. Canadian Blood Services
    Ms Elaine Ashfield, Legal Counsel and Privacy Officer

Appendix B: Oral Presentations to the Review Committee

1. IMS Health Canada	(Written Submission #1)
2. Consumers' Association of Canada (Alta.)	(Written Submission #18)
3. Workers' Compensation Board	(Written Submission #21)
4. Pharmacists' Association of Alberta	(Written Submission #34)
5. Alberta College of Pharmacists	(Written Submission #37)
6. Information and Privacy Commissioner	(Written Submission #40)
7. Canadian Mental Health Association	(Written Submission #49)
8. Value Drug Mart Associates Ltd.	(Written Submission #51)
9. Edmonton Police Services	(Written Submission #10)
10. Calgary Police Services	(Written Submission #46)
11. Canadian Institute for Health Information	(Written Submission #63)
12. Alberta Medical Association	(Written Submission #47)
13. Chabad Lubavitch of Edmonton	(Written Submission #68)
14. Government of Alberta	(Written Submission #67)
15. Health Boards of Alberta	(Written Submission #60)

Appendix C: Questions from the Consultation Guide

1. Are the purposes in the HIA appropriate? If not, please explain why and make suggestions for improvement. Would the inclusion of the additional purposes be acceptable?

2. Are there any definitions that should be modified? If so, kindly provide the rationale for the modification and any suggested wording.

3. Should the scope of the Act be expanded to include other departments of the Government of Alberta, local public bodies as defined in the *Freedom of Information and Protection of Privacy Act*, and to any other entity that is not a custodian and that has health information about the health of an individual in its custody or under its control?

4. Should operators as defined in the *Ambulance Services Act* be included in the scope of the Act?

5. Should the scope of the Act be changed given the implementation of the Electronic Health Record? If so, how? Please provide the rationale for the suggested changes.

6. Should health service provider information be included within the scope of the Act?

7. Should personal health information contained in employee health files be part of the scope of the *Health Information Act*?

8. Should the scope of the HIA be extended to include the WCB?

9. Should Alberta Blue Cross be subject to the HIA for all health information as defined by the HIA in its custody or under its control?

10. Should the definition of health information be changed to include non-recorded information?

11. Is the process for obtaining access to records appropriate?

12. Are the exceptions to the individual's right to access their own information (both mandatory and discretionary) appropriate?

13. Is the amount of fees set out in the Health Information Act Regulation appropriate?

14. How should the HIA be amended to address the concept of custody or control of a custodian within the EHR?

15. Is the duty to collect health information directly from the individual except as authorized appropriate? Are there other legitimate circumstances for indirect collection?

16. Should custodians be permitted to collect information about the individual's family health history without the consent of the family members where necessary to provide health care to the individual? Or should privacy protection of the individual not allow this collection?

17. Is the requirement to inform individuals about collection practices effective or does it create any operational difficulties?

18. Are the purposes as currently listed in the Act appropriate for existing custodians?

19. If you recommended an expansion of scope of the Act to include other entities, what purposes/set of responsibilities would you change to reflect the mandates of additional custodians?

20. Is it appropriate to use identifying health information without consent for the authorized purposes stated in the Act?

21. Overall, should the listing of authorized uses be expanded, restricted or modified in any way?

22. Are the elements of consent appropriate? Or should consent be allowed to be provided verbally to the custodian and if so, what are the implications?

23. Are the discretionary disclosures without consent (subject to overriding principles) as listed in the Act reasonable and appropriate? Should these permitted disclosures be restricted in any way?

24. Should the discretionary authority to disclose to police services without the individual's consent be extended to disclose basic registration information to police services for purposes of providing a warrant, subpoena or court order?

25. Do you disagree with the proposed amendment to specifically reference the triplicate prescription program?

26. Should the HIA be amended to include stronger provisions to protect the confidentiality of genetic information?

27. Is an informed/knowledgeable implied consent model for care and treatment appropriate for Alberta's health system?

28. Are the research provisions in the Act reasonable, effective and operationally effective?

29. Are the duties and obligations on the custodian appropriate and reasonable?

30. Do you have any suggested changes to this part of the Act (the Commissioner)?

31. Is the list of substitute decision makers appropriate?

32. Are the offences and penalties appropriate?

33. Are there any suggestions for improvement to the rules contained in the *Health Information Regulation?*

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